

Talking to children

A guide about support for children and young people dealing with incurable illness or the death of someone close to them



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You are probably reading this because someone close to you has a life-limiting illness or has died.

Here at St Helena, we provide specialist support for children and young people up to the age of 18, who have someone close to them (i.e. a family member) who is living with an incurable illness. We also offer bereavement support to children and young people grieving the death of a loved one, regardless of how or where they died. You do not have to be known to the hospice to refer your child/family to our bereavement service.

Not all children will need support from our service, but we are here to offer information, guidance, and reassurance to parents and carers on how to support their children if needed.

As a hospice, we believe the more we are able to talk about death and dying as being a natural part of life; the less scary it can become.

Our staff and volunteers are deeply committed to working with children impacted by the loss of a loved one. We are aware we cannot protect children from loss, but we can help them in processing the pain of loss.

Like adults, young people respond to bereavement in many different ways. Sometimes the experience can make them more vulnerable to health problems, lower self-esteem, isolation and detachment. Nothing can take away the sadness when someone dies. However, with the right support, we can help children to feel good about themselves and enable them to find ways to manage their worries and uncertainties. By doing this, children and young people, together with their families, can overcome the disadvantages associated with bereavement.

We appreciate that while we have tried to consider multi-cultural needs, some of this guide may not relate to your beliefs and the rituals that influence the expression of grief.

The following guide has been put together to help adults feel more comfortable to approach the subject of incurable or progressive illness and bereavement.



The importance of talking to children

Telling a child that you or someone they love has an incurable illness can feel like a daunting prospect. Parents and carers may wish to protect children from knowing about the seriousness of the illness. It may be that the person is undergoing treatment with the hope this may improve their condition.

Whatever the reasons, children will notice changes to their world; this is inevitable. Whether these changes are big or small, children/young people will sense when something is wrong and can tell when adults around them are upset or anxious.

Children of all ages often know more about what is happening than adults realise; it is often the 'not knowing' that causes problems. Often children overhear adult conversations, and can invent their own explanations if they are not given information, which can leave them feeling worried and upset.

They may not feel able to ask questions due to their young age or vocabulary. Often they just don't know what to say for fear of upsetting their parent or carer. They may feel they are to blame for the situation or just not important enough to be included in a conversation.

Whatever the reason, it may feel like there is never a right time to have a conversation. However, we know children who are not given the opportunity to talk about things openly may feel alone and frightened because they do not know what is happening. Often what children imagine can be far worse than the reality.

Letting your child know they are welcome to ask any questions about what is happening in your family can help to encourage more open conversations. If you do not have the answers to a child's questions, be honest and tell the child "I don't know". There may be another family member or a health professional who can answer the child's questions. However, sometimes there are questions about death and dying to which there are no answers and it is important for children to learn there are some questions even adults cannot answer.

In our experience of working with parents and carers, we have learned it is important to give children the chance to talk openly about their fears and worries.

Children/young people need:

- Age appropriate information
- The opportunity to ask questions and express their feelings
- Sensitivity to what they know
- Simple and honest explanations
- Careful listening
- Acceptance of their feelings
- Praise for being brave enough to ask their questions

Children may react to the serious illness of someone close to them in a variety of ways. There may be changes to their mood or behaviour; some may keep their feelings inside; and others will express their feelings, concerns or worries and show you how they are feeling.

Supporting children through illness and loss is not easy. The balance of wanting to protect children and knowing the 'right thing' to say can feel impossible at times. Ask them to tell their story about what they think death and dying is. This can help you to understand and correct anything that may not seem quite right. Encourage them to ask questions, and be prepared to answer the same questions over and over again. Children need short, easy to understand explanations.



When someone is approaching the end of life

Generally, parents/carers are the best people to talk to a child when it becomes clear a person's health is deteriorating and they are going to die. It is important to find out what your child already knows or has been told, then you will need to have what is likely to be one of the hardest conversations you will ever have with your child and finding the right words may not be easy. However, being honest with your child will give them time to prepare and an opportunity to say goodbye.

Sometimes parents' initial thoughts might be to not tell their child as they want to protect them, or they are frightened how their child might react. Not talking about it will not prevent the person from dying. Excluding children from these conversations can leave them feeling upset and angry. There is also the risk of them hearing this information from another source.

It is important to prepare children for what they are likely to experience at the bedside of a dying person. Often children who have a parent/grandparent living with them at home will have already seen the gradual changes. Some children will need lots of information but for others they will only need 'in the moment' information. Follow the child's cues for how much or how little information they want.

Throughout the illness process, it is helpful to reassure the child that they will continue to be involved in the care of the dying person. However, this can be difficult for children to know how to interact with someone who is dying, when the person is spending all their time in bed or has little energy to engage. Here are a few suggestions:

- Decorate the room
- Ask the child to tell them about their day
- Hold hands
- Choose and listen to music

Some children may find it too difficult to spend time with the person who is dying and they should never be forced to do so, or made to feel guilty. However, they can still maintain connections with the family member by drawing them a picture, or sending them a card, flowers or recording. For more information on this, you can request our 'Staying in touch' leaflet.

It is often helpful to talk to children about how they want to find out about the person's death. Would they like to be told in school, or prefer to be picked up and told at the end of the day? Ask if they are hoping to be with their dying family member when they die and explain you will make every effort to do so, but it is not always possible to know exactly when someone may die.





When a loved one has died

Explain someone has died clearly, simply and honestly...

Children need to know what happened to the person that died. Talking to children about death is really difficult when you feel you don't know what to say or how to say it; addressing it helps children to know that it's okay to feel sad and to ask you questions. Talking to a child about death can help them feel better supported and more secure.

Common myths are that children do not grieve and they are too young to understand. Even though children may not understand the actual meaning of death, they feel the loss of close relatives in much the same way as adults. It is clear that, even from infancy, children grieve and feel great distress, sadness, anger, worry and many other feelings.

St Helena would recommend you talk to your child as soon as possible. Waiting for the 'right time' can cause confusion and resentment and the 'right time' sometimes never comes.

Use clear language they can understand. You may like to use the following words to help you to explain what has happened:

"I've got something very sad to tell you. You know mummy (daddy, nanny, grandad) was very, very ill. Sadly died today at the hospital/home/hospice. We all feel very sad." Or "I have something very sad to tell you about daddy. He had a terrible accident and sadly he died today. We all feel very sad."

Don't say they have "gone to sleep" or "gone away" as this can confuse and frighten a child; they may feel too frightened to go to sleep in case they never wake up or they may continue to look for the person who has died.

Explain honestly why they died; "They died because they had cancer/motor neurone disease/a heart attack/were in an accident."

Say that "the doctors tried very hard to make the person better; to fix them; but sometimes the body cannot be fixed"; or "the person was very, very ill and the medicine did not make them better."

Do not feel you have to give children all the information in one go. Think about it like a jigsaw, giving little bits of information so your child can build up a picture over time so they understand.

Day, weeks, months later they may ask you another question like: "How did daddy die in an accident?"

You may respond: "Daddy was driving his van and it crashed. Daddy hit his head. The doctors tried very hard but they could not mend his head and he died. If your head is badly hurt, your body stops working and you die."

Questions and reassurance

Ask if your child has any questions and answer honestly. Admit if you don't know an answer.

Children may not understand what 'dead' means. You can say: "When someone dies the body stops working and the person no longer breathes, eats, moves, hears, talks or feels pain. They can't feel anything when they are dead; it doesn't hurt and they are not in any pain. They cannot come back to life once they have died."

Make sure your child knows the death was not their fault. Many children believe that something they thought, said or did caused the death. Reassure your child they were not responsible.

Be prepared to explain over and over again what happened, even if the child was present at the death. Very young children will ask the same questions multiple times as they do not understand that death is final.



Children may ask things like:

What exactly happened when my dad died?

Did anyone see him die?

Was he in pain?

Did it hurt?

The child might be frightened that they are going to die too. Knowing why someone has died can allay some of these fears.

Children may have questions around who will take care of them; will they have to change schools?

There are no set answers. It's best to be as honest as you can. Most children prefer to have information rather than to guess and worry about what might happen.

Feelings

Don't be afraid to show your child your own feelings. It's alright to cry in front of the child. It can help to let them know why you are crying. You could say: "People cry for lots of different reasons, especially when they are sad; it is a way of expressing their sadness because someone close to them has died." Let them know it's also ok not to cry, if that's how they feel.

Children can feel fearful and insecure so let them know they are loved and there are still people who will be there for them. A cuddle makes a huge difference.

Remember that children don't want to talk about their feelings all of the time. They need time to be children too.

Viewing a body with a child

Viewing a body with a child may seem like a grown up thing for a child to do, but for some children, the opportunity to see the body of the person who has died can be reassuring, particularly if they were unable to say goodbye before the death.

With the right information and support, children are usually able to make their own decision about going or not, and although very sad, children can manage this sad experience. It is good to reassure them they can change their minds about seeing the body right up until the last minute.

If your child wants to have a viewing, it is very important your child is well prepared. It may be helpful to organise a viewing for yourself first, without your child, as this will allow you to experience your own initial feelings and reactions, without having to support your child at the same time. It will also allow you to describe what you have seen to the child in order to prepare them.

It is helpful for children to know the following before viewing the body:

- The person, or people who will come with them.
- The location of the dead person – at home, chapel of rest, hospital bed, hospice.
- Where the deceased will be – in a bed or in a coffin.
- What the person will be wearing – nightwear, fully clothed in their red dress, football T-shirt.
- It is important for the child to know that the person will look pale and feel cold to touch. It is always helpful to explain that this is because the blood has stopped pumping around the person's body.
- It is important to reassure the child that if they have changed their mind this is ok as well. Children should not feel pressured into doing something they do not want to.

After viewing the body, children may have questions, or want to talk to someone, or stay physically close to you for comfort. Or they may want a distraction and go to see their friend. **Be led by your child. It is not unusual for a child to just carry on as if nothing significant has happened; often reactions come later, when they have had time to think about the situation.**

There are also other ways for children to say goodbye if they choose not to see the body. You could encourage them to do a drawing or pick a flower which you can leave with the body on their behalf.

Funeral/memorial/ceremony/ritual

Making the decision as to whether or not children should attend the funeral may feel difficult to do, particularly if your child is very young. However, children are part of the family and excluding them from an occasion where other family members are present can leave a child feeling isolated, whatever their age. Funerals are important to people of all ages because they help us to acknowledge that someone has died. They assist us in the early stages of grief, and help us mark the death according to our own religion or philosophy.

Children are no exception. They too need the opportunity to say goodbye, so encourage your child to attend the funeral service/memorial service/ceremony. Sharing information about where the funeral will be and what people may be wearing, will help a child to build a picture of what to expect. Try not to overload the child with details, but be led by their questions and what they want to know.

Although a funeral is very sad, with good preparation and support, children can cope with attending. If your child is reluctant to attend, gently mention they may regret missing out on this important day. However, do not force your child to do anything against their will.

Nowadays, more and more children make their own contributions to funerals by sharing something they have drawn or made in memory of their loved one. Older children may wish to select some music or write something and read it aloud during the service or alternatively ask another person to do this for them.

It can be helpful and reassuring for children to sit next to someone they have a good relationship with, in case they wish to leave the service. It is comforting for a child/young person to know there is an option to leave the service at any point should they wish. Even if a child is unable to stay for the duration, it is important they still feel part of the event.

If children do not attend the funeral, there are other ways to help children feel part of the day. Children may ask an adult to take a picture they have drawn to the funeral on their behalf. Photos can be taken of the flowers and given to the child along with an order of service for them to keep.

Just like adults, children may find the experience of attending a funeral painful and upsetting, but this is likely to be the same for everyone. It can also be an opportunity to share happy memories about the person's life and a chance for adults and children to have an opportunity to say goodbye.



These are only suggestions. Remember every child is an individual and you need to adapt your answers depending on the child, their stage of development, the situation and your beliefs.

What next

If your family believes in survival of the spirit or afterlife, or has any specific religious belief about life after death, find some way to talk about this belief with your child. The most important thing is to be honest. Children may ask you lots of questions. It is OK not to know all the answers.

Playgroup/school college

We recommend you inform your child's playgroup/school/ college as soon as possible so they can support your child. **It is helpful for them to know the circumstances of the death and the words you have used so they can be consistent if your child asks questions.**

Some children want to go back to their playgroup/school/college straight away, whilst others want to stay close to their family. Support your child in what feels right for them and you. Seek guidance and support from the playgroup/school/college if your child has difficulties going back after the funeral.



Puddle jumping

Remember that grief for children can be like 'puddle jumping'. Crying and talking about the deceased one minute and the next running around, playing and having fun. It can be so quick that it is called 'puddle jumping'; the puddle is their feelings of grief and they move quickly in and out of the puddle.

Grief for children can be episodic; it may fade only to re-emerge at a later date as the child develops and they need to re-visit their grief. This can be years later, particularly if the child was very young when someone died.

It takes a long time for children as well as adults to fully understand and adjust to the loss of a loved one. The four tasks of mourning are generally accepted to be:

- Accepting the reality of the loss
- Working through the pain and grief
- Adjusting to a world without the deceased
- Finding a connection with the deceased while starting out a new life

The last task refers to the continuing bond theory of grief. Some psychologists have moved away from the idea of 'letting go' of the

deceased and instead embrace the theory relating to 'continuing bonds'. This means for some people, especially if the relationship was good, keeping a connection with the deceased becomes a healthy part of life. Writing them a letter or keeping photos of them around, talking about them to new people. However, it is important this does not stop the person from moving on with their life, building new relationships and being happy within them.

How children understand death

A child's understanding will depend on many things. These include age, development, personality, family background and previous experience of death. **No two children develop at the same rate, so be led by your child and don't be afraid to tell them if you don't know something.**

It is now recognised that very young children including babies, do experience grief, they just show it different ways. Children's understanding of death and bereavement will be different at different stages of development. Although a child's grief is individual, their understanding of the loss of a loved one will progress as they mature.

Birth to six months

Babies do not cognitively understand the notion of death, but this does not mean to say they do not respond to the loss of someone close. A baby will notice if their main caregiver is absent.

Some common reactions may include:

- Feeding and sleeping difficulties
- Crying

Six Months – 2 years

At this age they will have no understanding of what death and dying means, but at around two they will start to notice the absence of familiar people. Bereaved toddlers can actively try to seek out the deceased person, by searching for them in places they might normally hope to find them.

Some common reactions may include:

- Sleep problems and tummy aches
- Looking for the person
- Clingy behaviour
- Inconsolable crying and being generally sad

Age 2 – 5

At this age, children may talk about death and think it is reversible. They may ask questions such as, where the person is, or when they might see them next. They are unable to understand that death is permanent. Support the child by encouraging them to ask questions, and answer them openly and simply.

Some common reactions may include:

- ‘Puddle jumping’ – e.g. sad one minute then goes out to play the next
- Problems sleeping and nightmares
- Clingy behaviour and behaving inappropriately for their age
- Needing reassurance you are not going to die too, and that death is not their fault
- Worry about who will care for them
- Regression in language skills and toilet training
- Repeatedly asking the same questions

Age 5 – 10

Children from about the age of 7 begin to realise that death is the end of the person’s life, the person who died won’t return and death is permanent and inevitable. Children will ask many questions and may want to know what happens when someone dies. It is vital that children have such details explained to them clearly so they understand.

Some common reactions may include:

- Regressive behaviour
- Getting angry more often
- Loneliness and sadness

Adolescents

Adolescents, will have a better understanding of death. They may worry about who will look after them, or where they might live. They may think about the long term impact on their lives.

Some common reactions may include:

- Finding it difficult to talk about their feelings
- Intense feelings, such as anger, guilt, sadness



- Choosing to talk to friends rather than an adult
- They may bottle up their feelings and want to avoid talking about it
- Feeling badly about themselves
- Worrying about illness and how it relates to them

Children with learning disabilities

Children and young people with learning disabilities may find it harder to understand the concept of death. When you are talking to them about the person who died, it might be helpful to repeat the information and keep checking if they have understood what you have told them. Encourage them to ask questions and talk to you about how they might be feeling.

Some children may find it helpful if you use reassuring behaviour, like holding their hand, particularly if they find communicating difficult or are non-verbal.

Grief reactions:

Following a death, children may experience various reactions:

Emotional responses may include anxiety, confusion, sadness, relief, isolation and guilt.

Physical responses may include unexplained aches and pains, low energy, interrupted sleep patterns.

Behavioural responses may include aggression, irritability or regression more commonly associated with younger children (bed wetting, baby talk, thumb sucking).

Social responses may include loss of confidence, self-esteem and withdrawal from friends and activities.

These are all natural reactions and they will pass.





Bereavement support

Not every bereaved child and family needs professional support.

Although the death of someone special is a very difficult and painful experience, many bereaved families manage this with the support from their own family, friends, schools and the community around them.

If you feel you and your family needs further support, St Helena is here to help and our bereavement support is provided free of charge.

Our team will provide an assessment of your needs. Following this, we will mutually agree on what support would be best in your circumstances. Support can vary from family to family.

We also:

- Offer talking therapy and creative ways in which to support children
- Help children and families create memory boxes
- Support children to 're-visit' their experience as they develop and transition through life

How to refer to us

You can refer your child and/or family for bereavement support at our website: www.sthelena.org.uk/bereavement

Someone who is supporting you or your child, such as a healthcare professional or family member, can also refer you with your consent.

Useful websites and resources

Winston's Wish

Helpline: 0808 020 021, Monday to Friday, 9am – 5pm

ask@winstonswish.org

www.winstonswish.org

Cruse Bereavement Care

Helpline: 0808 808 1677

www.cruse.org.uk



Hope Again (young people living after loss)

Helpline: 0808 808 1677
hopeagain@cruse.org.uk
www.hopeagain.org.uk

Child Bereavement UK

Helpline: 0800 02 888 40
helpline@childbereavementuk.org
www.childbereavementuk.org/game-apart-of-me

Grief Encounter: supporting bereaved children

Helpline: 0808 802 0111, Monday to Friday, 9am – 9pm
griefftalk@griefencounter.org.uk
www.griefencounter.org.uk

Child Bereavement Network

www.childhoodbereavementnetwork.org.uk

Childline:

Helpline: 0800 1111 (24 hours)
www.childline.org.uk

Books for children

No Matter What (5+)

By Debi Gliori, 2003. Bloomsbury publishing Ltd

A fun and imaginative book that touches briefly about death to help support younger children through difficult times. This is a beautiful and lyrical picture book about enduring love, going on forever, even after death.

I Miss You

By Pat Thomas, 2001. Turtleback books

A first look at death, this book covers a range of issues as to why people die, in a simple, gentle way, explaining the feelings children will experience and answering questions.

I Have a Question About Death

By Arlen Grad Gaines and Meredith Englander Polsky, 2017.

A book for children with Autism spectrum disorder or other special needs, providing clear answers to children's questions.

What Does Dead Mean? (4+)

By Caroline Jay and Jenni Thomas, 2012. Jessica Kingsley Publishers.

This is an ideal book for parents and carers to read with their children. It is also suitable for professionals working with young children.

Always and Forever (3+)

By Alan Durant and Debbie Gliori, 2004. Corgi books.

This book emphasises the importance of holding onto memories, and has lovely colourful illustrations. It shows children that although loved ones may die, we can still hold happy memories of them.

Badgers Parting Gifts

By Susan Varley, 1984. Anderson Press.

This book tells the story of Badger's peaceful death, and his friends remember what Badger taught them throughout his life.

The Invisible String

By Patrice Karst and Geoff Stevenson, 2000. DeVorss & Co.

The invisible string talks about loneliness and separation from someone we love.

The Memory Tree

By Britta Teckentrup, 2013. Hachette Children's Group.

This book helps children share memories of someone who has died. When Fox lies down in the woods to die, his friends gather around to tell stories and celebrate his life.

Water Bugs and Dragonflies: Explaining Death to Young Children

By Doris Stickney, 1982. The Pilgrim Press.

A delightful simple story to answer some questions about death, by telling a story of a water bug's short life under water, and their emergence into the sun as a dragonfly.

Muddles, Puddles and Sunshine: Your Activity Book to Help When Someone Has Died (early years)

By Diana Crossley and Kate Sheppard, 2001. Hawthorn Press

Produced by children's charity Winston's Wish, this book offers sensitive support for bereaved children with helpful activities and exercises.

Sad Book (5+)

By Michael Rosen

This book reflects the sadness of the author when his son Eddie died, aged 18. The book is thoughtfully illustrated.

A Monster Calls

By Patrick Ness. Oxford University Press.

A bestselling novel about love, loss and hope. A boy seeks the help of a tree monster to cope with his mum's terminal illness. A magnificent tale of heartbreak, healing, courage and survival. This powerful novel is often used in schools and is listed as a teacher support tool.

Books for adults**Healing Children's Grief: Surviving a Parent's Death From Cancer**

By Grace H Christ, 2000. Oxford University Press.

The author uses research to study the grief process in different age children. This book enables adults to better understand how children process their grief.

As Big As It Gets: Supporting a Child When a Parent is Seriously Ill

By Julie A. Stokes, 1997. Winston's Wish.

A book that offers ideas for parents/carers so they are able to involve their children in what is happening.

Never Too Young to Know: Death in Children's Lives.

By Phyllis Silverman, 1999. Oxford University Press.

Intended for adults, this tells the stories of children and how they coped with death.





Family support team
(and out of hours): 01206 890 360

Bereavement team: 01206 984 274

The hospice: 01206 845 566

Fundraising: 01206 931 468

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